

**Can We Rest in Peace? The Anxiety of Elderly Parents  
Caring for Baby Boomers with Disabilities?  
Forum - Senate Special Committee on Aging  
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I am representative of the hundreds of thousands of families across this country who are afraid to die because we don't know what will happen to our sons and daughters when we are no longer around to care for them. We are fearful that they will be forced to live in large congregate settings, forced to leave their families and friends or forced to live in substandard housing because there is nothing else available. The title of your forum clearly states that fear.

In most states, the only way to get services for persons with mental retardation is at the time of severe crisis. Crisis is spelt in capital letters. Crisis means your caretaker is dead or dying. The service provided in that instance is disruptive. Not only is your parent dead, you are shuttled away to a new situation to live with people you do not know to fit into a "slot" that may or may not be suited to your needs. The state probably has to fund a "behavior specialist" because you are "acting out" your grief and frustration. It is quite evident from a common sense point of view that this is just plain wrong! From a public policy point of view, this "slot" is probably more expensive than would be necessary if it was provided with planning and participation of the individual and his/her family.

There are only three states that have attacked this problem and developed 5 year plans to eliminate the Waiting List in their states. The first of these is New Jersey under the leadership of Representative Frelinghuysen (a member of the NJ legislature at the time) and Governor Whitman. Maryland was the second state under the leadership of Governor Parris Glendening. I am biased being from Maryland but I think we have the best approach, we are implementing the Waiting List Initiative using principles of self-determination. In the last few weeks Governor Pataki of New York announced his plan to eliminate the Waiting List in his state.

You have a copy of The Arc's Report Card on Waiting List before you. Obviously, it was issued before Maryland and New York announced their Initiatives. Four states reported no waiting lists, California, Kansas, Nevada and Rhode Island. Rhode island has no Waiting List because they have used the savings from closure of their institution to fund services in the community. Iowa, Ohio and West Virginia have not created the capacity to collect data.

Once The Arc had issued the Report Card on the Waiting List, it became evident that we could not stop there. The Arc of the United States has launched a Waiting List Campaign. We have held four regional conferences around the country and are providing information and technical assistance to state Arcs and their partners to launch a campaign in their own states.

In Maryland, 40% of those on the Waiting List have caregivers over the age of 60. Yet, interestingly enough we are finding that families especially those who are elderly are not necessarily wanting a full blown set of services. Families are satisfied with in-home supports that assist them in the day to day caregiving. Often, Aging services for the caregiver have been combined with support services from the disability agency. They are pleased to be able to plan supports for a time when they cannot provide the caregiving. Sometimes these plans include leaving the family home to the individual. Other times they are involved in the search of compatible housemates and appropriate housing.

All families and individuals are not alike and there are many situations where our sons and daughters want to move out of the family home and get a life of their own. In all of these situations, when an individual and family can be involved in planning, a majority of the time, the services cost less than they

would have if waiting for a crisis.

I want to tell you a little bit about my own situation. My son John is 32 years old and has mental retardation. He does not speak very well, but he has great communication skills in his own way. He works every day on a variety of recycling jobs. Collecting trash and recyclables is his thing. He puts out the trash for five or six neighbors, walks the neighbor's dog every day and is often hired by neighbors to help with a variety of chores. In his spare time, he patrols the local shopping center and gas station picking up recyclables.

The highlight of the week is Saturday morning. I prepare a deposit slip for his check so he may go the bank. From the bank, he goes to the local Giant Supermarket to shop and hangs out in the breakroom for a couple of hours. As the staff, including the manager, take breaks, they sit and eat with John buy him donuts and drinks. After he finishes at the Giant, he stops to greet the people at the gas station, the local Lido's Restaurant (although he doesn't like pizza) and ends up at the liquor store to buy a six pack of O'Douls. After putting his groceries away, he visits with our neighbor Charlie. John is happy, is accepted as a participating member of our community. I don't worry about his safety or mistakes, because someone would let me know. Would it make any sense to move him out of that community away from everything he loves when I die?

We have made provisions to leave our home to John and move support services in as he needs them. He will need a good deal of support but not as much as moving him away to an unknown setting. This arrangement is good for John, it is good for our family because we know John will continue to be happy and good for the taxpayers because John will be receiving the supports he needs, no more or no less. While we had this plan for John in mind before the Waiting List Initiative, I am very relieved to know that the plan can be implemented when it is needed. John would have to be in severe crisis to receive services and time of severe crisis is no time to implement an innovative plan.

In each of the states that has an Initiative, the federal partnership is a key element in creating solutions to this very serious problem. There are many issues to be addressed by Congress to facilitate the elimination of these Waiting Lists. We families who have sons and daughters with mental retardation are looking to you for help.

The Individuals with Disabilities Education Act (IDEA) has had a tremendous impact on the lives of kids with disabilities and their families. Since children are educated in our communities, the expectation of these adults and their families will be community supports.

## **Critical Issues**

**Medicaid** -The most important factor in the three states with Waiting List Initiatives is Medicaid. All three states are using the Medicaid Waiver to help fund the community services. Yet Medicaid funding is very biased towards institutions. in spite of the fact that there is no or very little demand for institutional placements. We have a situation in this country with "haves and have nots". We have people in very expensive institutional settings with costs as high as \$250,000 a year per individual and people who have no services at all. I would like to point out that persons with very similar disabilities are being served in the community at much lower cost. We would like to see that change to favor supports that are driven by individual desires for freedom and responsibility.

HCFA has recently written to state Medicaid Directors advising them of court decisions that have determined that the American with Disabilities Act prohibit ongoing institutionalization if professionals have determined the resident can be served in the community. I believe we will see a number of states

taking those decisions very seriously and use the opportunity to downsize and close institutions. These decisions affect nursing homes and mental health hospitals as well as any state funded facility for people with disabilities. A review of this bias to large congregate settings is way overdue.

Housing - Another very important issue to solving the Waiting List problem is housing. Because of their disability, the vast majority of individuals on the Waiting List are very, very poor. The unemployment rate for people with disabilities is 60% or more. Most people with mental retardation are either unemployed or work part time in minimum wage jobs. Their SSI or SSDI benefits are not enough to rent at market rates. HUD recently released a report to the Congress, "Rental Housing Assistance - The Crisis Continues. The report estimates the number of people with disabilities with worst case housing needs may well have grown to 1.1 to 1.4 million people. Households with worst case needs are defined as unassisted renters with incomes below 50 percent of the local median who pay more than one half of their income for rent or live in substandard housing.

The Housing Appropriations bills coming out of the House and the Senate include an additional funding for Section 8 tenant based rental assistance specifically for people with disabilities, increases for the Section 811 program and a recommendation that nonprofits become eligible applicants for tenant based rental assistance funded with Section 811. (Only Housing Authorities are eligible at this time.)

We would also like to see support for requirements that ensure that funds from both the HOME and CDBG programs are targeted to people with mental retardation and other disabilities. Melwood, an agency serving persons in Prince George's and Charles Counties, assisted 22 people to purchase their own homes in the community with the help of HOME funds. These folks had stable jobs and SSI or SSDI benefits. They qualified for a purchase of a home because Prince George's County and the state or Maryland granted Melwood funding to assist these purchasers with downpayment and closing costs.

### **SSI and Social Security Disability Policies -**

The House passed HR 3433 earlier this year. This bill entitled "Ticket to Work and Self Sufficiency Act of 1998" reforms and improves the Supplemental Security Income (SSI) and the Social Security Disability Insurance (SSDI) work incentives program to assist people with disabilities overcome the barriers to work. Senators Jeffords and Kennedy have introduced their own bill that simplifies provisions from the House version.

Current policies to encourage and support persons with disabilities to work and live independently need substantial reform. The vast majority of persons with disabilities want to work (including people with mental retardation) but are unable to make the leap from SSI/SSDI benefits and health coverage to sufficient wages to afford independence and health coverage. A person has to choose to stay poor with SSI/SSDI and health coverage or get a part time, low paying job without benefits and be very poor. Not a very good choice.

With a gradual reduction in benefits, a person with mental retardation can at least have a minimum wage job and maintain some degree of independence. This is crucial to eliminating the Waiting List. It is awfully hard to live on your own without resources of some kind!

### **Other Issues**

1. Expansion and improvement of transition, job training and employment
2. Reauthorization and funding of Family Support Program

3. Opening access to generic programs such as rental and homeownership; job training and employment; access to health care and transportation.

In 1987, The Arc conducted the first ever study of waiting list. At the time we found a total of 152,896 services needed. Ten years later, the number has jumped to 218,186 services. Additionally, there are people in institutions waiting to move to the community. To describe the waiting list situation as a crisis for America is no exaggeration. Further, because of the data gathering mechanisms used by states, as described in the report, The Arc believes the true picture of need is understated. We believe that the Senate Special Committee on Aging can play a unique role in raising the awareness of this issue. The Waiting List is an issue in each of the 50 states. You can help aging parents find hope and peace by taking the leadership to start the process of finding a solution to this vexing problem.